Re-imagining social care services in co-production with disabled parents

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Introduction

Studies of disability and parenting have tended to focus upon 'parental impairment – rather than social disablement – as the key variable of interest' (Olsen and Clarke, 2003, p.1). Moreover, they have tended to assume a correlation between impairments and negative impacts on children's wellbeing. In contrast, this Disability Research on Independent Living and Learning (DRILL) and Big Lottery funded research project aimed to re-imagine social care services for disabled parents and their children, and to:

- problematise the assumption that having an impairment necessarily impacts on the ability to care for a child
- use the Social Model of Disability to move away from talking about impairments and onto exploring the systemic, attitudinal and environmental barriers that may prohibit or restrict disabled parents from meeting their parenting responsibilities
- work in co-production with disabled parents to develop potential solutions that aim to keep families together through independent living

Methodology

Researchers from the Tilda Goldberg Centre for Social Work and Social Care at the University of Bedfordshire worked with six disabled parents

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involved with Ginger Giraffe (a cooperative that brings disabled people and those experiencing multiple disadvantages together with health and social care students on placement). The parents had all been referred to (or self-referred to) children's social care and had undergone an assessment to determine whether their child or children were 'in need' or suffering, or likely to suffer, significant harm (under s.17 and s.47 of the Children Act 1989).

The group engaged in a process of Appreciative Inquiry using the 5-D cycle of Definition (agreeing the scope of the research), Discovery (stories about what is), Dream (imagining the best of what could be), Design (statements of intention) and Destiny (action planning) (Cooperider et al., 2000).

The central aims of the project were to:

- explore these six disabled parents' experiences of statutory assessments in children's social care services and subsequent service provision, including examination of:
    a) the assessment pathway (how they accessed support)
    b) the assessment itself (thresholds and eligibility criteria)
    c) principles guiding the assessment, and how these were experienced by disabled parents
- draw on disabled parents, child and family social workers and researchers' knowledge and expertise to re-imagine how children's and adults' social care might deliver holistic services which value the needs, assets and rights of the whole family

Between January and July 2018 over 25 meetings were convened to bring together the co-production team. Mixed methods were employed including: focus groups, service mapping, storyboarding (a process by which participants write their story against a timeline and present the people in their stories including their feelings and thoughts), use of needs assessment mapping, service suitability mapping, concept reframing mapping, snap shot big picture, fishbone diagramming and role play (see full report for further details).

The sample size for the study is small and a number of policy and practice developments have occurred over the period that these parents

were involved with services. However, we echo Dale's (2004) reflection that the views of parents 'can extend beyond the biases of their particular experiences and consequently can offer sophisticated and insightful contributions that are of much value in relation to the development of good practice' (p.138).

We also recognise that it would be valuable to hear the voices of a larger group of disabled parents, as well their children and to discuss decision-making processes and subsequent service responses with practitioners and managers.

Learning from disabled parents' experiences

Referral pathways and help seeking

Four parents spoke to health or adult social care professionals to request support to help them fulfil their parenting responsibilities. In each case parents were either told to get in touch with children's social care direct, or the professional concerned offered to make a referral. The responses in each of these cases suggested that health and adult social care professionals did not view any aspect of child care support to be within their purview[1]. For example, one parent was told:

> Regarding the baby, you will need to contact Children's Social Services, so she only helped me to the extent just to do with my care package, as a disabled person.

In the later stages of the pregnancy the nurse made a referral to children's services. No 'support' was offered but 'monitoring' ensued.

> The only thing she [the social worker] was concerned with was that because I'm disabled, there's a risk, full stop, that's the only thing she could see.

Although all the parents acknowledged that they would benefit from help they were also fearful about having contact with children's services.

> You don't want to call social services, you are scared to call them because they might think you are incapable of looking after the child, so you have to struggle with what you have because you are

[1] With the exception of an occupational therapist who assisted with arrangement for adjustment to a cot.

> scared to call to ask for help because then they will say, 'we told you she's disabled, she can't look after her child', so there's always that element of fear, of 'shall I or shall I not?'.

Subsequent experiences served to reinforce rather than ameliorate parents' initial fears about the involvement of children's social workers in their families' lives.

Assessments and meetings with children's social care

All the assessments were undertaken after the *Assessment for Children in Need and their Families* was implemented (Department of Health, Department for Education and Employment and Home Office, 2000). Underpinning principles of the Assessment Framework include working *with* children and families, building on strengths as well as identifying difficulties, and an inter-agency approach to the assessment and provision of services (Department for Health, Department for Education and Employment and Home Office, 2000, p.10).

Parents' accounts suggested that a number of these principles were not evident in practice. None of the parents felt they had been given enough information about the purpose of the assessment. They also reported that their voices were not heard and that their knowledge and expertise in relation to their own impairments was not adequately understood or recognised. Poor communication and lack of clarity about the social work processes they were the subject of served to heighten anxiety about children's services intervention in their lives. First encounters with children's social workers were not conducive to building effective working relationships. Rather than seeking to understand the family's perspectives on their needs, circumstances and desired outcomes they felt that social workers exerted power over them.

All the parents suggested that assessments were risk focused and deficit orientated and that the primary focus was parental (in)capacity. In the words of one of the parents:

> The professionals, when they asses us, they already have a negative perception and it's an ideological barrier, in the back of their mind they assess based on preconceptions…They have a

> negative attitude that you will remain disabled all your life, there's no cure, hence you are always a risk…You are seen and labelled as cared for, rather than as a caregiver.

Service provision

Children's social care provision

The research found a mismatch between the services and support that disabled parents thought would be helpful and what was available and offered to them. First, they highlighted that the services that were provided did not serve to support them to fulfil their parenting responsibilities, but instead involved providing substitute care which separated them from their children.

Second, two parents with mental ill-health requested support to avoid problems escalating, but found that early help was not provided; during times of crisis services were provided but on a time-limited basis. They were also withdrawn abruptly. They reflected that had more community based support been put in place earlier then emergency admissions to hospital and relapse might have been avoided, which would have been in their whole family's best interests.

Third, the parents described walking a tightrope – to demonstrate that they were eligible for assistance – but were not too needy for children's social care to deem them to be a risk. They highlighted that this would not be necessary at all if adult services provided them with adequate support to fulfil their parenting responsibilities.

Adult services provision and the relationship between agencies

Morris and Wates (2007) have identified the following as features of good practice in working together to support disabled parents:

- needs arising from the impairment/illness and/or disabling barriers were addressed before making judgements about parenting capacity
- there were good working relationships between agencies and disciplines

- service development and delivery were characterised by a partnership between agencies and disciplines
- there was a continuum of prevention

The parents' accounts suggested that these principles were not consistently embedded in practice. Overall, there was little evidence of joint working between children's social care and adult services, even though the value of working together and a preventative approach is acknowledged in policy and procedure documents. Instead, adult services were minded to assess the disabled parent as an 'individual' without any reference to their parental role and associated support needs. One parent explained that adult services were planning to discharge her from hospital to a nursing home until an accessible flat became available. 'Nobody had thought where are the children going to go?'. She was also assessed as needing practical support with cooking following her spinal injury. She was offered meals on wheels but this offer was not extended to her children.

The majority of the stories gathered from parents predated implementation of the Care Act 2014. The Act acknowledges that 'carrying out any caring responsibilities, the adult has for a child' should be considered when eligibility for services is being determined. However, since the legislation has been enacted two of the parents have made specific requests for for adult services to meet these needs, but have been refused and told to approach children's services. Slasberg and Beresford (2014) highlight that councils 'continue to have the power to define needs and have to do so within limited budgets' (p.1680).

Re-imagining social care services to support disabled parents and their children

Drawing on learning from disabled parents' experiences the co-production team moved on to imagine what an ideal model of support for disabled parents and their children might look like. The 'dream' of an alternative model of service and support sought to address a number of the barriers and challenges that the parents' stories illuminated. The ideas that are presented are intended to provoke discussion and debate in the disabled community and amongst policy makers and social care

professionals. We see this as the start of a conversation about approaches to protect and and promote the wellbeing of disabled parents and their children, not the final destination.

Beyond silos: Developing a specialist service

Parentability: The Disabled Parents' Partnership

The parents' proposed establishing a new dedicated and specialist service called 'Parentability': The Disabled Parents' Partnership, which would fulfil the following functions:

- upholding the rights of disabled parents
- hearing the voice of both disabled parents and their children
- keeping disabled parents and their children together
- enabling strengths and unlocking assets
- promoting disabled parents and their children's full participation in mainstream society

They thought it was important for the new service to sit outside current service structures and that it should be embedded in the community, in order to help overcome entrenched attitudes and models of working in adult and children's services. One parent expressed the dream as:

> A service that caters holistically for the whole of the family, which is inclusive, rather than changing and reshaping existing statutory services and then trying to shift their mind-set and their way of practice…

Being 'outside' children's and adult services was perceived to be important to minimise fear and stigma. The parents also recommended that around 70% of the staff should be disabled. Both these developments were seen as important vehicles to alter power dynamics and to 'allow disabled parents to hold some of the power in the decision making process'.

Parents envisaged embedding a new assessment process that includes more opportunities for professionals to build relationships and rapport with disabled parents and their children, to facilitate the conduct of holistic family assessments (see the full report for further details).

In order to strengthen assessment and delivery of services for disabled parents and their children, the parents recommended use of the Disabled Parents Assessment Honeycomb (see Figure 1, below), which is based on disabled parents' recommendations on new principles to underpin assessments.

Figure 1: Disabled Parents Assessment Honeycomb

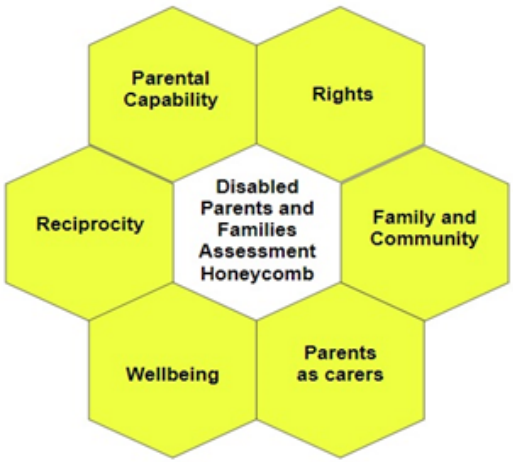

Table 1 below provides some examples of what the principles mean to parents.

Table 1: Principles underpinning the Disabled Parents Assessment Honeycomb and parental perspectives on their importance

Principle	Ilustrative quote
Parental capabilities	Parental assets, strengths, skills [need to be recognised] and there needs to be acknowledgement of what we are able to do…Strengths based is looking at the strengths we have and then acknowledging where we need support.
Reciprocity	It's about shifting the power dynamic…it's about professionals allowing disabled parents to hold some of the power in the decision making process.
Family and community	It's about mapping out the support that disabled parents may have and looking at those support

	networks…its about keeping the family together and thinking about the family as a whole, not adults and children separately.
Parents as carers	Recognise us as parents (not simply as people who need to be cared for) and provide services to support us to fulfil our parenting responsibilities.
Wellbeing	Having a sense of worth, confidence and esteem in the presence of professionals when working towards solutions and being part of the decision-making process enables my wellbeing. Also, being allowed to say how I want things to be and not being judged because of my circumstance. Wellbeing for me is a life without stigma.
Rights	Uphold the rights of disabled parents (including the UN Convention on the Rights of Persons with Disabilities 2006; Equality Act 2010)

Conclusion

Messages from the disabled parents in this study are broadly consistent with national and international research exploring service users' experiences of child and family assessments and child protection practice (see among others, Buckley, Carr and Whelan, 2011; Dale, 2004; Dunbrill, 2006; Gaffar, Manby and Race, 2012; Gallagher et al., 2011; Harris, 2012). Findings revealed that the involvement of children's social care provoked fear and anxiety and that parents felt that they were under surveillance and being monitored and judged rather than offered support. There was limited evidence of health and social care services working together to provide support for the whole family. Instead, there was a mismatch between the support that parents wanted and needed for their family (practical support) and what was available and offered (short term substitute care).

The research served to illuminate specific barriers and challenges facing disabled parents. First, we found that a lack of accessible housing, equipment, schools, hospital wards and transport adversely affected disabled parents' ability to support their children and that these disabling barriers were not addressed (even thought these matters should be addressed before making judgements about parenting capacity) (Morris and Wates, 2007). Second, parents highlighted how societal attitudes towards disabled parents meant they were generally perceived to be needy and dependent and judged on their incapacities, rather than on their strengths and resilience. Third, the findings revealed that health and adult social care professionals did not appear to view any aspect of child care support to be within their purview even though family life and caring responsibilities should be taken into account (Care Act 2014). It was acknowledged that austerity measures meant that thresholds for services and support were (too) high and that this had detrimental consequences for disabled parents and their children. They called for tailored and preventative support services to avoid the escalation of difficulties (rather than short term crisis interventions, including the provision of substitute care which separates children from their parents rather than supporting parents to fulfil their parenting responsibilities).

In re-imagining services responses to protect and promote the wellbeing of disabled parents and their children the parents placed rights (rather than needs and resource led decisions) at the heart of practice. They called for greater recogniiton of the social, economic and environmental realities of disabled peoples' lives, whilst also drawing on the strengths and resources within local communities. They aspired to see greater recognition of their parenting capacities and strengths and for professionals to work with them to provide tailored packages of support for the whole family. These suggestions are not intended to be the last word, but part of a wider debate on supporting families. It is worth noting that the proposals resonate with wider calls to re-imagine child protection and to adopt more humane and strengths and rights based practices which promote social justice (Featherstone et al., 2018).

Recommendations

- Routine collection of statistical data to establish the number of disabled parents in the UK and to establish the nature and extent of service provision to support these families
- Further research to examine the degree to which adult and children's social care are meeting their statutory responsibilities towards disabled parents and their children
- Acknowledgement that disabled parents and children are 'experts in their own lives'
- Recognition of parental capabilities and strengths
- Greater attention should be given to the economic, social and cultural barriers faced by disabled parents and the impact these have on the whole family
- Rights-based rather than needs-led and resource driven decision-making
- A clear and integrated assessment pathway that moves beyond service silos
- Moving beyond individually-orientated, reactive and crisis driven approaches to meeting needs
- Tailored and preventative support services to prevent the escalation of difficulties (rather than short term crisis intervention or the provision of substitute care which separates children from their parents, rather than supporting them to fulfil their parenting responsibilities)
- Coordinated support that meets the needs of the whole family
- Local services that promote family and community engagement

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